

## Mothers Health Awareness Toward Their Children Undergoing Congenital Heart Surgery

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### Abstract

**Background:** Congenital heart defect is the second cause of death in infancy and childhood and is the leading cause of childhood morbidity and mortality. congenital heart surgery corrects heart defect that a child is born with it, enhance mothers knowledge and practices toward their children undergoing congenital heart surgery help child to recover early and prevent complication. **Aim:** this study aimed to assess mothers' knowledge and reported practices toward their children undergoing congenital heart surgery **Setting:** this study was conducted at outpatient clinic of Cardio Vascular and Thoracic Academy Ain Shams University Hospitals **Sample:** 70 mothers and their children undergoing congenital heart surgery were included in this study. **Tools of data collection:** two different tools were used. **First tool:** consist of interviewing questionnaire to assess socio demographic characteristic of mothers and their children, knowledge, reported practices of mothers for their children undergoing congenital heart surgery, **Second tool:** Assessment of child health status. **Result:** revealed that 81.4% of the studied mothers achieved poor knowledge scores. Only 18.6% of them achieved average score and 91.4% of the study sample total mothers' practice was unsatisfactory. **Conclusion:** there was no a statistical significant relation between the mother's knowledge and reported practices ( $P > 0.05$ ). **Recommendation:** Comprehensive, multidisciplinary discharge planning should design early and should include the mothers and children contain education regarding congenital heart surgery care, providing mothers with discharge care of their children after congenital heart surgery should become a routine practice to congenital heart surgery department to enhance fast recovery and prevent complications.

**Key words:** mother's knowledge and practices, children with congenital heart surgery.

### Introduction

Congenital heart defect (CHD) is a defect in the structure of the heart and great vessels which is present at birth. Many types of heart defects exist, most of which either obstruct blood flow in the heart or vessels near it, or cause blood to flow through the heart in an abnormal pattern (Lozano, 2020).

Congenital heart disease is defined as a gross structural abnormality of the heart or intra-thoracic great vessels that is actually or potentially of functional significance (Tantchou et al., 2020).

Worldwide, CHD are the main heart diseases found in children and have been recognized as a major contributor to childhood morbidity and mortality, especially in developing countries (Chelo et al., 2016).

Globally, the prevalence of CHD is eight cases per 1000 live births across the globe, representing 1.35 million newborns each year with CHD in which more than half of them need surgery during the first year of their lives. The disease differs from one country to another, in America 6.61 per thousand live births, in the UK, 3.17, in Finland 1.95, in Denmark 6.18, in Sweden 3.57, in Australia 4.31 and in Canada 12.5 per 1000 live birth. In Egypt the prevalence was 1.0 per 1000 in Egyptian children (Kouame et al., 2020).

Cardiovascular surgery witnessed enormous advances during the past century with good outcomes. Unfortunately, the majority of children with CHD in developing countries are deprived of necessary care hence leading to high morbidity and mortality. Early detection of CHD is necessary to improve the quality of life and to

reduce morbidity and mortality of children (van der Linde, et al., 2015)

Mothers must understand the underlying cardiac defect and the goals' and objectives of the surgical repair ,in addition to normal child care ,mothers need to learn about care of the incision ,nutritional support and how to safely administer prescriptive medications, potential complications and when to call health care provider or seek emergency care are an important focus of teaching ,information about child development challenges specific to their child and pragmatic strategies to support normal development are of prime interest to mothers. Written reference materials a web resource list and enhance mothers' knowledge and reported practices (Pye and Green, 2016).

The role of nurses is to provide information regarding the disease, its treatment, prognosis and complication, also adjusting the child emotional as well as physical reaction to illness and hospitalization. The nurse should become familiar with parent and learn how to reassure them without minimizing the danger of the defective surgery. The nurse should teach the parents how to deal their cardiac children before and after operation until the discharge from the hospital (Wong, 2016).

### **Aim of the Study**

This study aims to assess mothers knowledge and reported practices toward their children undergoing congenital heart surgery through;

1. Assessing mothers' knowledge regarding care for their children undergoing congenital heart surgery.
2. Assessing mother's reported practices regarding care for their children undergoing congenital heart surgery.

### **Research Question:**

- 1- Is there relation between Growth and Development of Children According to Denver Developmental Screening Scale and their age?
- 2- Is there relation between Growth and Development of Children and their

demographic characteristics, and their mothers' demographic characteristics?

- 3- Is there relation between the mother's knowledge and reported practices during toward their children undergoing congenital heart surgery?

### **I-Technical design:**

The technical design used for the study discussed the following four categories, study design, setting of the study, subjects of the study and tools for data collection.

### **Study design:**

A descriptive study was used to assess mothers' knowledge and reported practices toward their children undergoing congenital heart surgery.

### **Setting:**

This study was conducted in outpatient clinics of Cardio Vascular and Thoracic surgery hospital at Ain Shams University Hospitals.

### **Sampling:**

#### **Type:**

Purposive samples of 70 of mothers and their children undergoing congenital heart surgery They are characterized by their children undergoing open heart surgery.

Aging from 2 years to 5year.

#### **Size:**

Sample size was calculated using **Epicalc, (2000)** software with the following inputs:

- Type I error ( $\alpha$ ) =5% with confidence level 95%
- Study power 90 % (power of test) with type error II 10% (Beta)
- The significance level ( $\alpha$ ) at 0.05

Data from a previous study (Lind et al., 2014). The total sample size from mothers and their children undergoing congenital heart surgery were taken according to this Formula

$$n = \frac{N}{1 + N(e)^2}$$

Where 'n' is sample size.

'N' is number of year (Dec 2017 to Dec 2018) at cardio vascular and thoracic academy Ain Shams University Hospital=472.

'e' is coefficient factor=0.05

**The minimal sample size was 70 mother and their children undergoing congenital heart surgery.** It includes children undergoing heart surgery children aging from 2 years to 5 years.

#### **Tools of data collection:**

The following different tools were used for data collection of study. It is developed by researchers after reviewing a related literature, expert's opinion and researchers experience to assess mother's knowledge and reported practices toward their children undergoing heart surgery.

#### **Tools of data collection:**

##### **Two tools were used for data collection**

##### **First tool: An interviewing questionnaire (Appendix I)**

It was prepared and designed by the researcher based on the recent related literature review and experts' opinion. It included five parts:

##### **Part (I): this part included:**

- (a) Socio demographic characteristics of mothers. This part included 3 close ended questions (Q1-Q3): such as (age of mothers, educational level, and occupation)
- (b) Children demographic characteristics. This part included 7 close ended question (Q4-Q10) such as: age, sex, Birth order, number of family member...etc)
- (c) Questions for mothers to assess health status for their children undergoing congenital heart surgery this part included 5 closed ended question (Q11-Q15): such as onset of the disease, its way of detection, follow up and if other family member suffered from the disease.

**Part (2):** mother's knowledge (Q 16-171) regarding to congenital heart disease concept, danger signs associated with an open heart surgery, daily activities, rest pattern, breathing exercise, nutrition,

incision care, oral care, medication, warning signs, follow up ...etc.

##### **❖ Scoring system of knowledge**

The score ranged from zero to one, the incorrect answers takes="(0)"grade & correct answers takes="(1)"grade.

The whole knowledge questions toward mothers of children undergoing congenital heart surgery scored 162 points, a total of 0- 50% (0-81) were considered poor knowledge and < 50%-75% (82-122) were considered average knowledge and <75%-100% (123-162) were considered good knowledge.

**Part (3):** regarding mothers' reported practices for their children undergoing congenital heart surgery, the rating scale according to items of each question, if mothers answered 60% or more from each questions items give score one, less than 60% give score zero.

##### **❖ Scoring system of reported practices**

Scoring system were ranged from zero to one, in correct practices level take"(0)" grade, and correct practices level take "(1) grade. The total score for all items related to practices 89 grade and was categorized into two levels as followings less than 60 % (0-53) un satisfactory practices and more than 60% (54-89) satisfactory practices.

##### **Second tool: assessment of child health status**

Assessment of child health status through physical examination of child growth and development using Denver developmental screening test (**Berman&Synder 2012**).

##### **Administrative Design:**

An official permission including the title and aim of the study were submitted from the dean of the faculty of nursing Ain Shams University and forwarded to the administrators of Cardio Vascular and Thoracic surgery hospital, to get an approval for data collection to conduct the study.

**Operational Design:**

The study to be completed passed through different phases included: preparatory phase, pilot study and field work phase

**Preparatory phase**

A review of the recent, current, national and international related literature covering all aspects helpful in designing and processing data collection tools using available textbooks, journals, and articles and nursing magazines to get a clear picture of the research problem.

**Pilot Study**

It was conducted on 10 mothers and their children undergoing congenital heart surgery the aim of the pilot study was to evaluate visibility and test the applicability of the developed tool and the clarity of included question, as well as the time required to fulfill the developed tools and carried out to assure content validity of tool as well as estimated the average time needed to complete all questions. Some changes were done accordingly. Those who shared in the pilot study were excluded from the study sample.

**Content validity:**

The tools were tested through five experts from community health nursing department, faculty of nursing, Ain shams university.

**The reliability:**

It was done by Cronbach's Alpha coefficient test which revealed that the tools consisted of relatively homogenous items as indicated by the moderate to high reliability of each g tool. The questionnaire was tested to be reliable with Cronbach's Alpha coefficient test of for items showed tool proved to be strongly reliable.

**Field work:**

After obtaining a permit the researcher meets the director of cardio vascular and thoracic surgery hospital and explain the aim and program content.

After permission the researcher started with introducing herself to the selected mothers

and their children and explain the aim of the study, assured that data collected will be confidential and will be used only to achieve the purpose of the study.

The researcher visits outpatient clinics of cardio vascular and thoracic surgery hospital two days or three days per week and take permission from mothers and their children for data collection and then take written consent from her to participate in the study and oral consent from the illiterate mothers, assured that the data collected will be confidential and will be used only to achieve the purpose of the study and to fill questionnaire sheet.

The study work was carried out within duration of three months starting from beginning of June 2020 till the end of August 2020.

**Ethical consideration:**

Approval was obtained from research committee of faculty of nursing, Ain Shams University. Issues of ethical consideration were discussed with the director of outpatient clinics and head nurses of outpatient clinics then mothers and their children including; privacy of information collected from them & freedom to withdraw from the study at any time. Then written approval obtained from literate mothers and oral approval from illiterate mothers to apply the study. Also head nurses attended some sessions that conducted in outpatient clinics and obtained a copy of the data collection tools and the program booklet.

**Study limitation:**

After congenital heart surgery especially during the immediate post-surgery period, the mother got tired and fatigue and refused the interview because they are afraid on her child.

**Statistical Design:**

Data were revised, coded, analyzed and tabulated using the number and percentage distribution and carried out at the computer, using appropriate statistical methods.

The following statistical techniques were used:

Percentage, Mean value, Standard deviation, Chi-square (X<sup>2</sup>), Correlation test (r) and Proportion probability (P-value).

#### Significance of results:

- When  $P > 0.05$  it is statistically insignificant difference.
- When  $P < 0.05$  it is statistically significant difference.
- When  $P < 0.01$  or  $P < 0.001$  it is high statistically significant difference.

#### Results:

**Table (1):** shows that 57.1% of mothers aged 20 years < 35 year, followed by 40% who aged 40 y. The mean  $\pm$  SD of their ages was  $31.34 \pm 5.9$ . Regarding their education, 25.7% of mothers continued their secondary education, 22.9% of them couldn't read or write. Also, 88.6% of their mothers were housewives.

**Table (2):** shows that 68.6% of children their aged between 6 months < 2 years old, 71.4% were females, 94.3% of those children had siblings. Also, 40% of them were the third birth order. 60% had 5 – 7 members in their

#### A-Socio- Demographic characteristics for mothers of children undergoing congenital heart surgery.

**Table (1):** Distribution of mothers of children undergoing heart surgery (n=70).

Items	NO	%
<b>Age:</b>		
• <20 y	2	2.9
• 20- <35y	40	57.1
• 40 +y	28	40.0
<b>mean <math>\pm</math> SD</b> 31.34 $\pm$ 5.9		
<b>Min</b> = 18 years <b>Max</b> =38 years		
<b>Mother's education</b>		
• Do not read or write	16	22.9
• Read and write	6	8.6
• Primary education	7	10.0
• Preparatory education	5	7.1
• Secondary education	18	25.7
• University education	18	25.7
<b>Mother's job</b>		
• A housewife	62	88.6
• An employee	8	11.4

families. The family income of 77.1% of them wasn't enough to their family needs. Additionally, the crowding index ranged from 1-4 with mean  $\pm$  SD of  $1.90 \pm 0.98$ .

**Figure (1):** shows that 81.4% and more of the studied mothers achieved poor knowledge scores, Only 18.6% of them achieved average score.

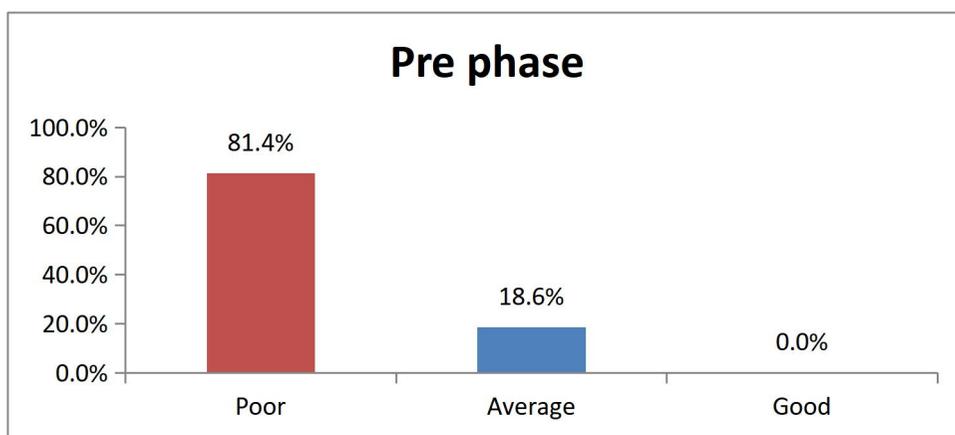
**Figure (2)** shows that 91.4% of the study sample total mothers' reported practiced was unsatisfactory in the pre-implementation phase.

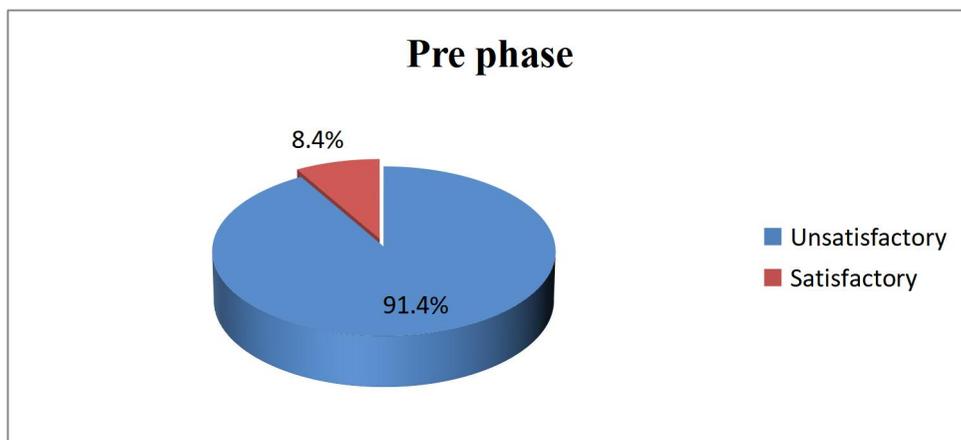
**Table (3):** detects that there is a statistical significant relation between growth and development of children and their demographic characteristics except "the child had siblings", and "arranging the child".

**Table (4):** shows that there is no a statistically significant relation between the mother's knowledge and reported practices ( $P > 0.05$ ). 74.3% of those mothers with poor total knowledge scores had unsatisfactory levels of practice. Only 1.4% of those mothers with average total knowledge scores had satisfactory levels of practice.

**B- Demographic characteristics for children undergoing congenital heart surgery.****Table (2):**Distribution of study sample children undergoing congenital heart surgery (n=70).

Items	NO	%
<b>Age:</b>		
• 6 months-<2 years.	48	68.6
• 2years -< 3.	11	15.7
• 3-<4.	7	10.0
• 4 -5.	4	5.7
<b>mean ± SD 1.56 ± 1.1</b>		
<b>Min= 6 months Max=5 years</b>		
<b>Gender</b>		
• Male	20	28.6
• Female	50	71.4
<b>Presence of sibling</b>	66	94.3
<b>Birth order</b>		
• First	10	14.3
• Second	8	11.4
• Third	28	40.0
• Fourth	20	28.6
• Others	4	5.7
<b>Number of family members</b>		
• from 3-4 member	22	31.4
• from 5-7 member	42	60.0
• from 7-9 member	6	8.6
<b>Family Income</b>		
• Not enough to family need	54	77.1
• Enough to family need	16	22.9
<b>Number of rooms in the house</b>		
• Two rooms	34	48.6
• Three rooms	32	45.7
• >Three rooms	4	5.7
<b>Crowding index mean ± SD 1.90 ± 0.98 Range ( 1-4)</b>		

**Figure (1):**Mother's total knowledge toward their children undergoing congenital heart surgery (n=70)



**Figure (2):** Mothers' total reported practices toward their children undergoing congenital heart surgery (n=70).

**Table (3):** The relation between Growth and Development of Children and their demographic characteristics, and their mothers' demographic characteristics

Variable	Growth and Development of Children						X <sup>2</sup>	P value
	Delayed		Normal		High accuracy			
	No	%	No	%	No	%		
<b>Age in years</b>								
6 months-<2 years	35	87.5	12	52.2	1	14.3	28.9	<0.000**
2years -< 3 years	1	2.5	5	21.7	5	71.4		
3-<4 years	3	7.5	4	17.4	0	0.0		
4 -5 years	1	2.5	2	8.7	1	2.5		
<b>Gender</b>								
Male	1	2.5	16	69.6	3	42.9	32.96	<0.000**
Female	39	97.5	7	30.4	4	57.1		
<b>The child have siblings</b>								
No	1	2.5	2	8.7	1	14.3	2.10	>0.05
Yes	38	97.5	21	91.3	6	85.7		
<b>Arranging the child</b>								
First	3	7.5	5	21.7	2	28.6	9.60	>0.05
Second	6	15.0	2	8.7	0	0.0		
Third	20	50.0	7	30.4	1	14.3		
Fourth	9	22.5	8	34.8	3	42.9		
Others	2	5.0	1	4.3	1	14.3		
<b>Monthly Income</b>								
Not enough	37	92.5	14	60.9	3	42.9	13.47	<0.001**
Enough	3	7.5	9	39.1	4	57.1		
<b>Mother's education</b>								
Do not read or write	13	32.5	3	13.0	0	0.0	27.93	<0.002**
Read and write	3	7.5	2	8.7	1	14.3		
Primary education	6	15.0	0	0.0	1	14.3		
Preparatory education	3	7.5	2	8.7	0	0.0		
Secondary education	13	32.5	5	21.7	0	0.0		
University education	2	5.0	11	47.8	5	71.4		
<b>Mother's job</b>								
A housewife	39	97.5	20	87.0	3	42.9	14.66	<0.001**
An employee	1	2.5	3	13.0	4	57.1		

(\*\*) Strong Significant at P < 0.01

**Table (4):** The relation between the mother's knowledge and reported practice toward their children undergoing congenital heart surgery (n=70).

Mothers' total Practices	Mothers' total knowledge						X <sup>2</sup>	P value
	Poor		Average		Good			
	No	%	No	%	No	%		
Unsatisfactory practices	52	74.3	12	17.1	0	0.0	0.016	>0.05
Satisfactory practices	5	7.1	1	1.4	0	0.0		

(0) Not significant at P > 0.05

## Discussion

### Socio demographic characteristics for mothers

The present study finding revealed that, more than half of mothers aged 20years<35 years and less than half of mothers aged 40 years, while majority of them were housewife. Regarding their education, more than one quarter of mothers continued their secondary education. Also, less than one quarter couldn't read and write. Regarding family residence, more than half of them living in rural area. As well as mother's job, more than three quarter of them were house wife.

This finding was in congruent with **El sobky & Amer, (2018) studied** " the effect of pre- hospital discharge program on mother's knowledge and reported practices for children undergoing congenital heart surgery" in Benha Egypt whose found that less than one half of mothers above 30 years and their mean age were  $30.80 \pm 3.27$  As regard mother's education less than half of them illiterate, while less than one fifth had the university. In relation to mothers' occupation, the majority of mothers were a housewife and half of them from the rural this could be attributed that interferes with an understanding of the steps recommended by the health professionals. Either in terms of health care procedures or the laws that guarantee their rights for their children

This result was in accordance with **Elsobky & Amer, (2018)** who conducted their study in Benha Egypt who mentioned that the mean age of both study and control groups were  $33.3 \pm 6.7$  and  $34.2 \pm 7.8$  years respectively. In relation to mother's education, more than two fifth in both study and control groups respectively were illiterate. Additionally, three quarters of mothers in the study group were housewife compared to more than two thirds in the controls. This could be

attributed that interferes with an understanding of the steps recommended by the health professionals. Either in terms of health care procedures or the laws that guarantee their rights for their children.

These findings were in agreement with those of **Abdel Salam & Mahmoud (2018) studied** "Effect of Educational Program on the Self- Efficacy and quality of life for mothers caring children with congenital heart disease, who reported that more than two thirds of mothers age between 26-35 years old. As regarding to education level of mothers, the result of the current study showed that more than one third of studied mother were in preparatory school

### Demographic characteristics for children undergoing congenital heart surgery

The current study result found that, less than two third of total sample of children having congenital heart surgery were female aged between 6 months-< 2 years old.as well as found that, the most of them had sibling. Regarding child birth order, less than half of them were third birth order. As well as found that more than half of them had 5-7 members in their families. Regarding the family income, more than two third of them were not enough to family needs (**table2**). This result was agreement with that of **Ujuanbi, (2016) studied** "Prevalence of Congenital Heart Diseases Among Primary School Children in the Niger Delta Region of Nigeria" who revealed that more than half of them were females. Also, these finding was incongruent with **El sobky & Amer, (2018)** who conduct his study in benha Egypt whose study entitled "The effect of pre-hospital discharge care program of mothers' knowledge and reported practice for children after congenital heart surgery" who revealed that more than half of children were male and presented at the age from 6 months to one year.as well as more than one third of the children in the study group as the

second infant. Also found that more than half in the group had previous surgery

Also this result was in agreement with **Sabaq & Abd El Sadak (2019)** studied "Effectiveness of Discharge Educational Program on Quality of Life and Post-Operative Complications for Children after Cardiac surgery" and mentioned that the mean age in both study and control groups were  $6.9 \pm 1.8$  and  $6.37 \pm 0.51$  years respectively. Regarding children's gender, showed that more than half of children in the study group was males compared to 65% of the controls. Regarding the child birth order, more than half in both study and control groups respectively were second birth order and the majority of cases were enrolled at primary level of education. In my out of view this result related to congenital heart disease is acritical case which effect on general health status of children.

#### **Mothers total knowledge toward their children undergoing congenital heart surgery.**

The study result showed that more than three quarter of the studied mothers achieved poor knowledge score. Only less than one fifth of them achieved average score.

These findings in the same line with **Sabaq & Abd El Sadak, (2019)**, who mentioned that 75% and 85% of the studied mothers in both study and control groups have unsatisfactory level of knowledge with no significant differences.

#### **Mothers total reported practices toward their children undergoing congenital heart surgery**

The study result showed that the majority of the study sample total mothers' practice was unsatisfactory in the pre-implementation phase, but the most of them were satisfactory in the post-implementation.

These findings were consistent with **Mohammed, et al., (2020)** who revealed that less than two thirds of the study sample had inadequate practice towards care for their

children with congenital heart diseases. these findings were in accordance with **El sobky & Amer, (2018)** who reported that the care activity as medication, diet, activity, wound care, etc showed that mother's practice of these activities had a highly significant difference in all items of care after discharge training compared with before the discharge training, this result in the same line with **March, (2017)** So discharge planning is very effective parts in caring for children after surgery, also should be an important component in the discharge program to ideal outcomes and reduce readmission of children to the hospital with further problems. The investigator sees, this results due to the importance of discharge plan post congenital heart surgery which contain child's activity, wound care and dental care to prevent endocarditis. Also to maintain child's health and prevent any complications.

#### **The relation between Growth and Development of Children and their demographic characteristics, and their mothers' demographic characteristics.**

The relation between Growth and Development of Children and their demographic characteristics **Table (3)** detected statistically significant relations between growth and development of children and their demographic characteristics, and their all the mothers' demographic characteristics except "the child had siblings", and "arranging the child".

These findings consistent with **Gürich(2016)** who mentioned that only 6% scored below the normal range of their age group. TFS sub scores were significantly correlated with age, bypass duration and motor function, but not correlated with socioeconomic status, duration of cardiac arrest, intelligence and academic achievement. Children with preoperative hypoxemia due to cyanotic cardiac defects in infancy are at higher risk for dysfunction in speech and language than those with cardiac insufficiency due to a cyanotic heart defects. Age at testing, socioeconomic status, and duration of cardiopulmonary bypass influenced test results. Long-term outcome in speech and language functions can be considered as a sensitive

indicator of overall child development after cardiac surgery.

### **The relation between the mother's knowledge and reported practices toward their children undergoing congenital heart surgery.**

The relation between the mother's knowledge and practices toward their children undergoing congenital heart surgery **Table (4)** shows there is no a statistically significant relation between the mother's knowledge and practices ( $P > 0.05$ ) less than three quarter of those with poor total knowledge scores had unsatisfactory levels of practice. Only less than one tens of those with average total knowledge scores had satisfactory levels of practice.

These findings were un similar with **Mohammed et al., (2020)** who demonstrated that there was highly statistical significant relation between their total practice and their total knowledge regarding CHDs ( $p$ -value = 0.001\*). Concerning the care activity as medication, diet, activity, wound care, etc. and mother's practice of these activities was had a highly significant difference in all items of care after discharge training compared with before the discharge training.

This result supported by **Abdel-Salam and Mahmoud, (2018)** who reported, more than half of studied sample were poor knowledge and reported practice respectively, and improved knowledge and reported practice score immediate post and after 3-month program.

The researcher's point of view suggests that, the mothers' needs to gain knowledge and practice regarding discharge care of their children after heart surgery. The educational session was effective in improving mothers' knowledge and reported practice. The session shows a significant effect increase of the mothers' level of knowledge which plays a significant role in the quality of care providing to children and effective outcomes.

### **Conclusion**

There was no a statistical significant relation between the mother's knowledge and

practices during pre-discharge plan ( $P > 0.05$ ), 74.3% of those mothers with poor total knowledge scores had unsatisfactory levels of practice. Only 1.4% of those mothers with average total knowledge scores had satisfactory levels of practice.

### **Recommendations**

**Based on the current study findings the following recommendations were proposed.**

- Providing mothers with discharge care of their children after congenital heart surgery should become a routine practice to congenital heart surgery department to enhance fast recovery and prevent complications.
- Further researches to examine the importance of discharge planning for congenital heart surgery for mothers and children.

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